

Colorectal and peritoneal oncology centre (CPOC)

Low Grade Appendiceal Mucinous Neoplasm (LAMN II)

What is it?

A low grade appendiceal mucinous neoplasm (LAMN) is a growth found in your appendix. If this is entirely contained within the appendix this is called a LAMN 1. However there are times when the growth has pushed through the appendix wall and this is called a LAMN II. This is where a small amount of mucous or cells may have leaked into your abdomen.

What causes it?

The cause of it is unknown but like any growth it can develop in people who lead a healthy lifestyle. There is no evidence that the growth can be transmitted through families or inherited.

Signs and symptoms

Most low grade mucinous neoplasms are found unexpectedly when patients have had their appendix removed for appendicitis.

How is it diagnosed?

Patients can often present with appendicitis and require an appendicectomy. Others have discomfort and are investigated with an ultrasound or CT scan and the appendix can appear enlarged (this is called a mucocele).

Treatment

Being diagnosed with a LAMN II means there is a risk cells may have leaked into the abdomen. In some cases this can go onto develop a condition called Pseudomyxoma Peritonei (PMP). This is a rare, often slow-growing tumour. It produces a jelly-like substance that collects in the abdomen. It does not spread through the blood or lymph nodes but stays in the abdomen increasing in size. To reduce the risk of developing PMP we offer a specialised operation called cytoreductive surgery and hyperthermic intra-peritoneal chemotherapy (HIPEC).



Cytoreductive surgery

There is evidence to show that a special surgical technique called 'cytoreductive surgery' where any potential areas of disease are removed can be helpful in reducing the risk of PMP. This treatment can involve major surgery to remove organs in the abdomen and the peritoneum. This process removes any potential small areas of mucin as well as removing areas that are at risk of developing disease. The surgery takes a whole day and may be performed open or keyhole (laparoscopic). Your surgeon will tell you what is most appropriate for you.

Are there any alternatives to cytoreductive surgery and HIPEC?

We can monitor the situation closely with regular CT scans and blood tests due to the risk of developing PMP. The tests will be performed 6 monthly for 2 years, annually up to 5 years and a further scan at 8 and 10 years. If there were any signs of disease developing we could reconsider surgery at that stage.

Laparoscopic cytoreductive surgery

Keyhole surgery is an alternative way to perform surgery for a wide variety of conditions if the person and condition is suitable. Keyhole surgery is carried out through small cuts in your skin rather than a bigger cut down the abdomen (open). Because the wounds are small, it means you can get better more quickly and leave the hospital earlier. It allows you to return to normal activity quicker and reduces the risk of developing other problems such as chest infections and hernias.

There is a 1 in 20 chance the procedure cannot be performed with keyhole surgery. In this case you will need to then have a larger cut.

What does this type of surgery involve?

Because your bowel and other parts of your body are tightly packed under your skin, there is not much room for the surgeon to work inside. To create more space for your surgeon to work, a small amount of carbon dioxide is used to inflate your abdomen.

Your surgeon works through small cuts made in your skin and uses a laparoscope, a tiny sophisticated telescope connected to a video camera, to carry out the operation. The operation will always involve removing the belly button, the gall bladder, the falciform ligament (a bit of fatty tissue between the belly button and liver), the omentum (fatty tissue) and in women sometimes one or both of the ovaries (this will be decided by your surgeon).

The surgery can take between 6-9 hours. You will also be kept in a special area in theatre to recover from the anaesthetic for a further 2 hours. Following the laparoscopic procedure you will generally be moved back to the surgical ward. However, in some cases you may go to critical care for observation overnight.

What complications can occur?

Complications include;

- Infection (common)
- Bleeding (requiring a blood transfusion is uncommon)
- Blood clots on the lungs (uncommon)
- If a section of bowel is removed; a leak where the bowel is joined together (uncommon)
- Injury to adjacent organs such as the bladder, tubes to the kidneys (ureters) or small intestine (rare)

Why would you not be able to have the surgery laparoscopically?

Sometimes the laparoscopic method cannot be performed on some patients. This decision is made by your surgeon either before or during the actual procedure. Some of the reasons may include;

- Obesity
- A history of abdominal surgery causing dense internal scar tissue (adhesions)
- If the surgeon is unable to see the internal organs
- Bleeding during the operation
- More disease than expected

HIPEC

Once the cytoreduction has been performed (open or keyhole), heated chemotherapy drugs are then put into the abdomen while you are still under the anaesthetic to kill any tumour cells. This is a process called hyperthermic intraperitoneal chemotherapy or 'HIPEC'. A combination of using a chemotherapy drug in a heated fluid that is circulated through the abdominal cavity helps to destroy and remove any cells that could otherwise develop into PMP. The surgeon puts 4 tubes into the side of the abdomen and a machine/pump is used to circulate and heat the chemotherapy which is mixed with fluid. After up to 90 minutes the chemotherapy is washed out and the abdomen is closed in the normal manner.

Two regimens of chemotherapy are used. Most commonly, Mitomycin C is heated to 42 degrees centigrade and put into your abdomen for 90 minutes. The second regime uses a combination drug given to you by an intravenous drip (5-Fluorouracil) as well as the heated abdominal chemotherapy (Oxaliplatin) for 30 minutes).

Side effects

Whilst this is a commonly performed procedure here at The Christie, cytoreduction and HIPEC is a significant operation to have and consequently complications/side effects can occur. Most of the side effects are from having the operation rather than as a direct result of having the chemotherapy (HIPEC).

Serious complications are rare and include bleeding or infection and may require a return to the oncology critical care unit or theatre. Minor complications e.g. mild infections, wound problems or clots in the calf veins (DVT), but these are often managed quickly and easily. Unfortunately there is a risk of death as a result of this treatment, but this is very rare.

Side effects from chemotherapy agents (as opposed to the surgery) are minimal but may include:

- Nausea and vomiting (sickness) – the severity of this varies from person to person. Anti-sickness medication will be given if necessary. After the operation you will have a tube in your nose that goes into your stomach, which will also help to stop you being sick.
- Prone to infection – the chemotherapy in your abdomen may cause a short-term transient drop in your protection against infection. This is seen by a reduction in the white cells in your blood (neutropenia). This is rare and is self-limiting after a few days.
- Delayed healing – the chemotherapy may slightly delay the healing process within your abdomen after the surgery.
- Lethargy/tiredness – some chemotherapy may make you feel tired and lacking in energy. This, in combination with major surgery, will mean you will need plenty of time to rest and it will be a while before you reach your usual energy levels.
- Diarrhoea – this may become a problem. However, it is more likely to be from the surgery itself rather than the chemotherapy.

All of these listed are only possible side effects. You may not experience any of them. Most of the chemotherapy stays in the abdomen rather than going into the blood, therefore most of the potential side effects will relate to the abdomen, for example, being prone to infection in that area, and delayed healing.

Fertility

HIPEC may affect your fertility. If you are planning to have children, please discuss any concerns about your fertility with your consultant and/or clinical nurse specialist (CNS) prior to your surgery. For women, surgery can involve removing the one or both of the ovaries and your surgeon will discuss this with you.

- For men, it may be possible to store sperm.
- For women, it may be possible to remove eggs, fertilise them with their partner's sperm and store them.
- For women who don't have a partner, it may be possible to remove eggs and freeze them so they may be fertilised later.

If you have intercourse post-surgery please ensure you use contraception for the first 6 weeks.

Preparation for surgery

You will be asked to come along to a pre-operative assessment clinic where you will meet a nurse who will check you are medically prepared for your operation. You will have a MRSA (Methicillin Resistant Staphylococcus Aureus) test before your admission to hospital. This involves taking a simple swab of your nose, throat and perineum (seat area). This is a routine procedure carried out on all patients who are admitted to The Christie for surgery. You can get more detailed information about MRSA from the infection control team, or ask one of the nurses.

We may ask you to have some pre-operative tests to assess your fitness prior to the surgery. This would include a breathing test (pulmonary function) and an ultrasound scan of your heart (echocardiogram). You may also be asked to have a cardio-pulmonary exercise test (CPX) where you will be asked to ride on a stationary bike breathing into a face mask.

The Christie has an online surgery school which can help you get ready for surgery and will also provide information for post-surgery. You can find this on www.christie.nhs.uk/surgeryschool

If your surgery is laparoscopic you will be put into the Enhanced Recovery Programme. This is to help patients recover more quickly following surgery. You will meet with the Enhanced Recovery Nurses who will go through this with you.

If you are particularly anxious about your surgery we have a complementary therapy team who you can be referred to for 'hypno calm' prior to surgery. Please ask your CNS if this is something you would like to be referred for.

If you are a smoker, it would benefit you greatly to stop smoking or cut down before you have your operation. This could reduce the risk of chest problems as smoking makes your lungs sensitive to anaesthetic. If you need help/support in stopping smoking we have a **smoking cessation** team you can contact **0161 956 1215 or 07392 278408** or you can contact your GP.

Before you come into hospital for your operation, try to organise things ready for when you go home. If you have a freezer, stock it up with easy-to-prepare food. Arrange for relatives and friends to do your heavy work such as changing your bedding, vacuuming and gardening and to look after your children if necessary.

Support

We know that people who have had a diagnosis can be affected in a variety of ways. For some people there will be physical concerns while others may have emotional or spiritual needs. Practical and financial worries can come to the fore during investigations and treatment and these can put significant strain on people. Most people want to be well informed and involved in decision making but people's information needs vary too.

Everyone is an individual and has their own concerns and needs. You will be offered a holistic needs assessment (HNA) by your CNS which is to help you to identify any concerns or needs that you might have so that we can then support you better. You will then be given a summary of your discussion in the form of a care plan. If you are not offered a HNA please ask your CNS who will be able to go through this with you.

Your CNS is there to support you throughout your treatment and if you have any questions/concerns or would just like to go through things again please do contact them on the number provided below. If appropriate and with your consent, we can refer you to a trained counsellor. We have a counsellor and a consultant psycho-oncologist on sight and if you feel you may be helped by these services please talk to your CNS to discuss a referral.

Visiting times

Visitors are welcome in the oncology critical care unit (OCCU), but only 2 - 3 visitors are allowed at the bedside at one time. Once on the ward, visiting is 2:00pm to 8:00pm and meal times are protected (12:00pm - 1:00pm and 5:00 - 6:00pm).

Consent to treatment

The colorectal and peritoneal oncology team will discuss the treatment that is recommended for you and explain how it will affect you.

We will ask you to sign a consent form agreeing to accept the treatment that you are being offered. The basis of the agreement is that you have had The Christie's written description of the proposed treatment and that you have been given an opportunity to discuss any concerns. You are entitled to request a second opinion from another doctor who specialises in treating this cancer. You can ask your own consultant or your GP to refer you. Your consent may be withdrawn at any time before or during this treatment. Should you decide to withdraw your consent then a member of your treating team will discuss the possible consequences with you.

Leaving hospital and coping at home

Recovery time after your operation varies from person to person. You may find it takes several weeks to feel better. You can expect a gradual improvement over the next 6 to 12 weeks.

Please follow these general advice points:

- You should not attempt to drive, lift or move heavy objects, do heavy housework (for example vacuuming, changing the beds) or start digging the garden until a minimum of 6 weeks following your operation.
- Getting back to work will depend on what type of job you do. Please ask if you are unsure. The ward should provide you with a sick note for your hospital stay, please ask before you go home. Your GP can then supply you with further sick notes.
- Getting back to normal activities and exercise will depend on you. It is safe to gently increase your levels of physical activity providing it is comfortable to do so.

Follow up after surgery

Your CNS will contact you once you are discharged home to check you are recovering well. We will then see you in The Christie outpatient clinic 4 to 6 weeks following your stay in hospital and you will then be reviewed at regular intervals.

Who can contact us?

Any health care professional who needs information or advice. Any patient coming for assessment or treatment for cytoreductive surgery and intraoperative intraperitoneal chemotherapy for colorectal cancer can contact the service themselves or by referral from another health care professional. We are also happy to speak to partners, friends and family, providing the patient has given consent.

If you know the name of your consultant, please contact their secretary directly.

Consultant	Secretary
Professor S T O'Dwyer	0161 446 8311
Mr M S Wilson	0161 446 3366
Professor A G Renehan	0161 918 2189
Mr C R Selvasekar	0161 918 2310
Mr O Aziz	0161 918 2057
Mr H W Clouston	0161 918 2391
Mr J Wild	0161 918 7352

Clinical nurse specialists:		
Rebecca Halstead (lead)	0161 918 7096 / 07766 780952	rebecca.halstead@christie.nhs.uk
Rachel Connolly	0161 918 7001 / 07785 725629	rachel.connolly@christie.nhs.uk
Lisa Wardlow	0161 918 7183 / 07826 892213	lisa.wardlow@christie.nhs.uk
Amanda Coop	0161 918 2097 / 07824 373785	amanda.coop@christie.nhs.uk

Clinical Nurse Secretary	0161 917 7859
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Key worker			
Your key worker (nurse)		can be contacted on	

If your key worker is not available, please leave a message on the answering machine with your name, date of birth and telephone number. All messages will be responded to as quickly as possible, but this may not always be on the same day.

If you have any problems after your operation, please contact the surgical oncology unit on 0161 446 3860.

Further information

For information about the colorectal and peritoneal oncology centre visit www.christie.nhs.uk/cpoc

Cancer information centre

The cancer information centre at The Christie in Withington stocks a wide range of booklets free to patients, their families and carers and offers a free confidential service for anyone affected by cancer. Contact: **0161 446 8100**.

Complementary therapy and smoking cessation

There is an outpatient drop-in service at The Christie on Tuesday and Thursday from 4pm. For complementary therapy – contact **0161 446 8236**. For smoking cessation contact **0161 956 1215** or **07392 278408**.

Maggie's centre

The centre provides a full programme of practical and emotional support, including psychological support, benefits advice, nutrition and head care workshops, relaxation and stress management. Maggie's Manchester is directly across from The Christie on Kinnaird Road. Contact Maggie's on **0161 641 4848** or email manchester@maggiescentres.org

Macmillan Cancer Support

This is a national charity offering advice and support. Call the freephone helpline **0808 808 0000** (Monday to Friday, 9am to 8pm) or if you are hard of hearing, use the textphone **0808 808 0121**. Macmillan Cancer Support publish booklets which are free and available on their website www.macmillan.org.uk

Hospital chaplaincy

Situated in department 57, on the first floor above the dining room and next to the education centre. We have a Christian chapel, a Muslim prayer room and a multi-faith quiet space. If you would like someone to visit you on the ward please ask a member of staff.

Useful websites:

www.pseudomyxomasurvivor.org (charity and patient forum)

Travel

Please see this helpful website for help with travel insurance. Ensure you state any diagnosis and treatment you have had: www.medicaltravelcompared.co.uk

We do have a very active research and education programme into Pseudomyxoma Peritonei here at The Christie and if you would like further information please see our website for details on our registered charity or ask your nurse specialist.

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

The Christie is committed to producing high quality, evidence based information for patients. Our patient information adheres to the principles and quality statements of the Information Standard. If you would like to have details about the sources used please contact **patient.information@christie.nhs.uk**

For information and advice visit the cancer information centres at Withington, Oldham or Salford. Opening times can vary, please check before making a special journey.



Contact The Christie Hotline for
urgent support and specialist advice
The Christie Hotline: 0161 446 3658
Open 24 hours a day, 7 days a week